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ABSTRACT

This paper reviews various discipline models and applies them to obtaining cooperation and compliance with medical treatment of children with chronic and acute medical conditions, especially End-Stage Renal Disease (ESRD). The definition of Other Health Impairments in the Individuals with Disabilities Education Act is cited and related to the medical, psychosocial, and educational characteristics and needs of students with ESRD. Seven conceptual models of behavior management are briefly described: biophysical, behavioral, humanistic, psychodynamic, ecological, cognitive, and psychoeducational. Management strategies based on each of these models are then proposed and organized into proactive strategies (to prevent problems) and reactive strategies (to solve problems as they occur). Each strategy is named, the model identified, and briefly explained. Examples of proactive strategies are: "I keep fit" (biophysical model), "catch'em being good" (behavioral), and "I am awesome" (humanistic). Examples of reactive strategies are: "The Me's" (psychodynamic), "get my drift" (ecological), and "stop, think, plan, and check" (cognitive). The paper stresses the importance of implementing discipline with dignity and collaboration with parents and other service providers in the implementation of any discipline strategy. (Contains 30 references.) (DB)

Running Head: CHILDREN WITH RENAL DISEASE AND BEHAVIOR MANAGEMENT

Discipline and the Chronically Ill Child: What are the Management Strategies to Promote Positive Patient Outcomes?

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ABSTRACT

Patients with End-Stage Renal Disease often present psychosocial problems which include noncompliance to treatment. Caregivers can, by understanding the various models of discipline, select proactive and reactive strategies to encourage cooperation and compliance. These strategies are grounded in discipline models which include the Biophysical, the Behavioral, the Humanistic, the Psychodynamic, the Ecological, the Psychoeducational and the Cognitive model. In addition, collaborative efforts with parents and professionals can enhance nurses' efforts and successful treatment of patients.

Discipline and the Chronically Ill Child: What are the Management Strategies to Promote Positive Patient Outcomes?

Students who are chronically ill are provided special instructional services under the provisions of the Individual with Disabilities Education Act (IDEA). The IDEA definition of these students incorporates their characteristics under the classification of Other Health Impairments (OHI) which is described as follows:

Having limited strength, vitality, or alertness due to chronic or acute health problems such as a heart condition, tuberculosis, rheumatic fever, nephritis, asthma, sickle cell anemia, hemophilia, seizure disorder, lead poisoning, leukemia, diabetes or any other medical condition that adversely affect a child's educational performance (U.S. Department of Education, 1992).

The IDEA definition of OHI is specifically stated to distinguish health impairments from other physical disabilities involving muscles, joints and bones. The emphasis is on chronic and acute conditions. A chronic condition is persistent and evolves over a long period of time and the child may need frequent and intensive medical attention. An acute condition develops quickly, needs attention, but can be overcome in a relatively short period of time (Turnbull, Turnbull, Shank, & Leal, 1995). Children

and adolescents who are chronically ill often experience stress and may develop psychosocial problems that result in academic regression, lack of compliance, loss of control and learned helplessness (Courts, 1994).

Students with End-Stage Renal Disease (ESRD) are classified as Other Health Impaired for educational purposes. ESRD is an irreversible anomaly of kidney function that is uncommon but can be usually survivable with treatment such as dialysis and kidney transplantation (Ericson & Riordan, 1993). Young people with ESRD miss many of the school social experiences because of frequent absences. They tend to be sheltered, are less involved in peer related activities and often lack independence and self-management skills (Fielding et al, 1985; Kutner & Brogan, 1985). In addition, they may exhibit anxious and depressive symptoms. Parker (1981) discovered that patients with high anxiety experience increased fluid overload, incidents of cramping during hemodialysis, and an increased number of clinical appointments due to problematic episodes. Anxiety is frequently experienced as uneasiness, apprehension, dread, and restlessness (Lambert & Lambert, 1985). Patients may exhibit their anxiety in passive and dependent behaviors; they may be excessively submissive and lack assertiveness and independence (Ericson & Riordan, 1993). Conversely, they may react aggressively and noncompliant. Their lack of compliance becomes a serious concern to their caregivers when it interferes with the treatment regime (Currier, 1993).

Nurses and parents can increase compliance and decrease negativity in a democratic and non-coercive manner when they understand the various models of behavior management and strategies from each of these models.

Models of Behavior Management

A variety of conceptual models have been proposed to explain and understand the causes and management of human behavior. Presently there is a tendency to recognize that each model has worthy considerations and that appropriate techniques can be used from each of the approaches: the Biophysical, the Behavioral, the Humanistic, the Psychodynamic, the Psychoeducational, the Ecological and the Cognitive models.

1. The Biophysical Model

The Biophysical Model, also referred to as Biogenic, and Biochemical proposes that human behavior has a physiological origin and is controlled by inherited traits, physical characteristics, or illnesses. Research has suggested a link between nutrition and personality disorders, and between neurological deficits and attention and hyperactivity problems. Other studies implied a relationship between allergies and behavior (Morse & Smith, 1991).

2. Behavioral Model

The Behavioral Approach assumes that behavior is learned from the environment. Behavioral interventions are based on two main assumptions: (1) the target behavior must be observable and measurable and (2) the consequences which follow the behavior must

be able to decrease or increase the behavior.

Behaviorist psychologists emphasize the Stimulus Response Reinforcement model (SRR), and consider reinforcement and punishment as the primary mechanisms for increasing or decreasing behavior. Reinforcers can be either positive or negative, and they are delivered following the occurences of desired behaviors. Punishment is a method used to decrease targeted behaviors (Alberto & Troutman, 1990). There are behaviorists who prefer to avoid punitive measures. They believe these methods may temporarily decrease unwanted behaviors but their use may also increases hostility and may be counter productive.

3. The Humanistic Model

According to the Humanistic Model, the goal of every human being is to develop their individuality and achieve self-fulfillment. Humans are set apart from other animals by their superior ability to think critically and to make decisions. Children are not lumps of clay to be molded or circus animals to be trained through reinforcers. Humanistic psychologists emphasize that human beings need to love and to feel loved, to experience self-esteem and self-satisfaction. The Humanistic Model values the differences among individuals and suggests that children will maximize their potential when adults accept them and guide them towards self-actualization (Maslow, 1969). Caregivers must provide a democratic and open climate in which children feel empowered and in control of their destiny.

4. The Psychodynamic Model

The Psychodynamic Model also referred to as the Psychoanalytic Model, views the cause of human behavior as within the individual. The roots of this model originated in the theory of Sigmund Freud (Freud, 1965). It focuses on the balance between the main parts of an individual's personality: the id, instinctual selfish needs; the superego, a controlling force over these selfish needs and the ego, a referee balancing control and selfishness.

Misbehavior is believed to be caused by too much restriction or too much gratification at certain stages of a child's development. Followers of this model propose that when adults are overly strict, children may displace their anger by being aggressive to peers or to younger brothers or sisters. These children may develop a negative self-concept and either grow up to be loners or nonconformists. They may become aggressive and rebellious or passive and indecisive. They are not able to get along with people and they resist any form of authority. Two fundamental ways in which caregivers can help the child according to the Psychodynamic model is: first, by accepting the child's behaviors and feelings; and second, by providing the child with opportunities for expression of feelings and impulses.

5. The Ecological Model

The Ecological approach assumes that persons are inseparable part of their social environment. This model was defined in the 1960's by Nicholas Hobbs and William Rhodes. They proposed that context affects behavior, and that children will misbehave and stop being productive when they are placed in losing situations. On the other hand, children will learn easily and feel confident when the situation is motivating and rewarding.

A child's ecology is complex with interactions happening between and within systems (Hobbs, 1975). Children who are constantly punished at home and in school will eventually succumb to their environment and turn either inward, in quiet desperation, or outward, in hostility and aggression. Situations and other people interacting with the child are considered to be influencing the behavior. Problems arise when there is a lack of fit between the child and other individuals in the environment. Children will alter their behaviors when the adults in their surroundings change their behavior or expectations, or when the children are placed in a different environment.

6. The Psychoeducational Model

Originally the Psychoeducational Model was associated with the Psychodynamic Model and employed many its strategies; however, it eventually added its own dimension. According to Long, Morse and Newman (1976) the Psychoeducational Model proposes that cognitive and affective processes are in continuous interaction and that

children can be taught and assisted to follow the rules of their social environment. Children must be taught proactively when and how to use prosocial skills in order to cope with the demands of their environment. The adults responsible for the children's welfare must set limits and boundaries but must avoid coercion. In addition they must be caring and loving, but must avoid unbridled permissiveness.

7. The Cognitive Model

The Cognitive Model is also referred to as the Social Learning Model. The lead proponents of this model are Bandura (1977), Meichenbaum (1979) and Mischel (1976). Followers of the Cognitive Model believe that human behavior is the result of a continuous reciprocal interaction between a person's environmental and cognitive, and affective influences. Several strategies from the Behavioral Model and the Ecological Model are used in the Cognitive Model approach. However, this approach differs from the Behavioral Model in that affective variables such as feelings and perceptions are taken into consideration. Unlike the beliefs of the Ecological Model, persons are not powerless objects controlled by the environment, nor are they free agents. Both people and the environment are reciprocal determinants of each other. Individuals' thoughts and feelings may impact their behavior; however, these are not independent of environmental occurrences and past experiences.

Management Strategies

Young patients with End-Stage-Renal Disease are often susceptible to psychosocial predictors which include depression, mood disturbance, life happiness, affect, pessimism, poor self-esteem, loss of control and power over important life domains, illness related concerns and difficulties in daily activities (Devins, Mann, Mandin, & Leonard, 1990). When choosing management strategies, the caregiver must consider such variables as the patients' maturity levels; maturity is defined as the patients' ability and the willingness to comply to the wishes of the caregiver. The second factor of importance is the nature of the situation. Each situation must be considered as unique with its own set of variables (Hersey and Blanchard, 1996). A caregiver must consider how the situation influences maturity level. A situation, such as a health related problem, may trigger immature behavior in an otherwise mature individual.

The interventions I have identified to promote positive patient outcomes are based on the various theoretical models of management and are incorporated into a two dimensional discipline paradigm. The two dimensions are:

1. proactive - strategies to prevent problems.
2. reactive - strategies to solve problems as they occur.

. **Proactive Strategies:**

*** I Keep Fit (Biophysical)**

Preventative medicine is a biophysical approach to foster wellness. Physical exercise, vitamins, diet and stress relieving procedures (biofeedback, relaxation techniques) are often recommended to facilitate individual sense of well being, social interactions and adaptation to the environment (Morse & Smith, 1991).

*** Catch 'Em Being Good (Behavioral)**

Caregivers can reinforce appropriate behaviors, and if possible, ignore inappropriate behaviors. For young children, they can use a token economy program, whereby tokens (stars on a chart, marble or beans in a small fish tank) are given every time they catch 'em being good. They can exchange the tokens for a coloring book or any tangible reinforcer. Pair each token with verbal praise. There are several ways to reinforce behaviors; behaviors that are incompatible with the targeted behavior may be reinforced (lying down is incompatible to standing), or reinforcing any other appropriate behavior the child demonstrates. In adjacent modeling, the nurse can reinforce the appropriate behavior of another child in view of the noncompliant child ; "Good Ken, you took your medicine, give me a high five."

*** I Am Awesome (Humanistic)**

Chronically ill children often lack a positive self-concept. They have poor self-image and a negative self-esteem. Humanistic strategies are designed to enhance appreciation and respect of self. Techniques such role playing, behavioral rehearsals, puppetry, and counseling can assist children to become aware of their strengths and to refrain from dwelling on their limitations. Caregivers can encourage children to write a list or to draw what they like about themselves. When children hesitate, the caregiver can initiate the list. In addition, by becoming aware and sensitive to the plight of others, children can gain insight into their own problems and feel comforted that they are not alone in their condition. Group sessions and sharing problems and solutions can satisfy social needs and increase motivation and cooperation. The use of humor can lighten frustrating situations. Caregivers can encourage creativity and motivation through visualization exercises, art projects and music activities.

*** I Know How You Feel: Bibliotherapy (Psychodynamic)**

Bibliotherapy is a strategy that uses reading materials relevant to the patients' health and emotional needs to help them better understand themselves and their predicament. Through identification with the story characters the patients may release stress and gain insight through empathizing with the problem described in the story (Russell & Russell 1979).

If appropriate books are not available, caregivers can, with the child's assistance, create a story with a fictional character. Be aware of the child's level of sensitivity to his or her weaknesses and avoid being too direct. The story can be written, computer generated, or typed and illustrated.

Steps for discussing a story:

1. Retell the story and emphasize the incidents, feelings, relationships, and behaviors expressed by the characters in the story.
2. Discuss changes expressed by the story characters of feelings, relationships, and behaviors.
3. Identify similar events from the child's life.
4. Explore alternative behaviors that may avoid the consequences reported in the story.
5. Draw a conclusion about the consequences or helpfulness of alternative behaviors.

*** The Great Communicator (Ecological)**

The quality of interactions between two persons is critical in determining outcomes. Gordon (1974) recommends an updated version of Carl Rogers communication techniques which includes a combination of environmental manipulation, active listening, communication through "I" messages, and awareness of problem ownership. He explains that "you" messages have a put-down effect, whereas "I" messages deal with the behavior rather than with attacks on the person. When the caregiver

owns the problem, an "I" message rather than a "you " message should be communicated. Such as: "Tom when I can't dispense the medicine, I cannot perform my duties and I become very concerned." Not, "You are not cooperating, you won't get better if you don't take your medicine. When the problem lies with the patient, the caregiver should listen actively. This involves listening to the feelings as well as to the words and avoiding put-downs, reproaches and other negative communication blocks. Active listening involves door-openers to encourage the flow of conversation, such as "I see what you mean"; "I hear you say that..."; "Tell me more about..."

*** I Am a Power Ranger (Psychoeducational)**

The democratic strategies of Glasser (1990) caution caregivers to avoid being authoritarian and coercive (boss managers) and to empower children by leading them towards appropriate resolutions (lead managers). Children and adults often engage in power struggles and the loser usually feels defeated and powerless. When children feel powerless, they retaliate through aggressive actions or they may withdraw into passivity. Caregivers can empower children by giving them choices, by including them in decision making and by informing them of their condition. However, caregivers must keep in mind that children need boundaries and that power and responsibility must be appropriated with caution and common

sense. Adults must use their power wisely and empower the children as they teach them to develop responsibility.

*** Thinking about Thinking (Cognitive)**

Cognitive interventions include teaching children self-discipline. Children can be guided to develop awareness by learning self-management strategies. These include self-instruction, self-recording, self-control and self-reinforcement. Caregivers can model thinking aloud (verbal mediation) and teach problem solving in a rational manner. At first children are encouraged to think overtly and are gradually led to think covertly. Children can be taught to give themselves cues (I'll take my medicine when the alarm rings) and to self-reinforce themselves (Good for me). Mediation and compromise skills are taught to resolve conflicts before they happen. Caregivers may use hypothetical situations and ask the patients to think of various solutions including compromises to solve the dilemma.

2. Reactive Strategies

*** I Need my Pill (Biophysical)**

Biophysical interventions include psychoactive drugs for physically induced psychological problems. Dietary adjustments and megavitamins have frequently been recommended for difficulties with personality disorders. Children diagnosed as having Attention Hyperactivity Disorders are

often prescribed such drugs as Ritalin or Cylert to control their lack of attention and activity level.

*** Grandma's Law: Negative Reinforcers (Behavioral)**

Similar to a positive reinforcer, a negative reinforcer is applied to increase a child's behavior. Natural negative reinforcers are found in the environment; if you play with fire, you will get burnt. A logical consequence or "Grandma's Law", is a consequence which emphasizes the "if"-"then" condition: "If you don't take your medicine, then you may not have your favorite ice-cream." There are many techniques within the behavioral approach to eliminate, targeted behaviors. Positive or negative reinforcement, response cost (fines), extinction (ignoring), time-out, token systems, contracting, slowly shaping a behavior, and exclusion from reinforcers. Punishment should not be used unless the behavior is life-threatening to self or to others.

*** Hear Me Out (Humanistic)**

Humanistic strategies appeal to the child's sense of fairness and responsibility without demeaning self-esteem. The Life-space interview is a humanistic intervention to manage a crisis or a daily problem. The caregiver must refrain from being judgmental and is simply a listener and facilitator. Morse (1975) outlines the steps of life-space interviewing as following:

1. The child or adolescent is allowed to give her impression of the occurrence or problem without interruption.
2. The caregiver listens without casting judgement, he may ask questions to determine the accuracy of the child's perception of the problem.
3. The child is encouraged to make a plan to solve the problem. If the child cannot solve the problem, the caregiver may have to suggest an acceptable plan.
4. The caregiver and the child work together to develop a plan for solving similar problems in the future.

Children with ESRD often experience learned helplessness. They become dependent on others and hesitate to express their feeling or their needs. Assertiveness training includes teaching children to become their own advocates. Through self-assertion, they develop self-esteem and confidence. Richardson (1996) developed a social skills program based on three theoretical frameworks, Cognitive Behavior Modification, Transactional Analysis and Assertion Training. Children are taught to be empathetic assertive while considering the other person's feelings. Assertiveness is contrasted and compared with aggressiveness and non-assertiveness.

*** The Me's (Psychodynamic)**

Children must be familiar with the different ego states of Transactional Analysis (TA) to be able to recognize which

behavior they are demonstrating. TA defines three ego states, the Parent, the Child and the Adult.

The Parent state comprises the attitudes and behavior incorporated primarily from our parents. It is often expressed in an authoritarian critical and controlling manner, or in a caring, nurturing and loving fashion.

The Child state contains all the impulses that come naturally to young children. The Child state can be impulsive, untrained, expressive and enthusiastic. It can be affectionate and uncensored. It can also be rebellious, fearful, self-centered and manipulative.

The Adult state is not related to a person's age. It is reality oriented, objective and reviews factual information before reaching conclusions. It thinks and solves problems logically.

In the Working Together program, Richardson (1996), refers to the Parent state as the Bossy Me and the Caring Me, the Child state is referred to as the Enthusiastic Me and the Impulsive Me, and the Adult state is the Thinking Me. Various songs and activities were developed to teach TA to children in grades K-5. Freed (1990, 1991, 1993) developed strategies for young children and adolescents using the framework of TA. When children are non-compliant, they are reminded to analyze their attitude and behavior and identify which Me they are using.

They can be directed to use their Thinking Me (Adult) to make decision or to solve their problem.

*** Get My Drift (Ecological)**

Ecological interventions consider the fit between the behavior and the setting. Collaborating with families and social service providers are ecological interventions designed to improve patients' compliance to treatment. These include frequent interactions with the families and eliciting assistance from psychologists, psychiatrists, social workers and counselors.

Psychodynamic and Psychoeducational strategies may be used to alter the child's milieu and consequently change the behavior. The following interactive and environmental interventions were adapted from Long and Newman (1971) to maneuver inappropriate behaviors:

1. **Planned Ignoring:** Many behaviors will stop if they are ignored rather than given attention.
2. **Signal Interference:** The use of a cue (shake your head) can alert a child to stop a behavior.
3. **Proximity Control:** Some disruptive behavior can be prevented or decelerated by the caregiver's presence.
4. **Interest Boosting:** Some behaviors can be managed when the caregiver shows a special interest in the child as an individual.

5. **Tension Decontamination through Humor:** Humor releases tension and increases children's ability to cooperate. Be careful that the humor is not perceived as sarcasm.
6. **Sympathize with Sense:** Deliver sympathy in a caring and encouraging manner, and elicit cooperation.
   "I do believe it hurts, I'll loosen the band aid, but what can you do to take your mind off the pain?"
7. **Distract and Divert:** Children will not dwell on problems when their interest is diverted to something else.
8. **Antiseptic Bouncing:** Change the child's environment (if possible, send him on an errand to the nurse's station) if you foresee an impending explosion.

* **A Line in the Sand (Psychoeducational)**

Placing Boundaries and Facing Consequences

Driekurs (1972) defines four reasons why children misbehave: Attention, Power, Revenge and Helplessness. He proposes strategies for reacting to these causes. Attention should not be given on demand and when given, should focus on positive rather than on negative behaviors. When interacting with power-seeking children, caregivers should control their anger and refuse to become part of the power struggle. To help the revengeful child, they should not retaliate, but should improve their relationship with the child by remaining composed and by showing care and concern. Driekurs strongly urges caregivers to place boundaries for children and together

plan logical consequences and to hold them responsible to these consequences. Dreikurs also strongly recommends group meetings to discuss, to teach, and to nurture loving relationships.

Glasser (1990) believes that children should be given choices in a democratic climate, but that they should also be held accountable. Children can be held responsible for their actions without punishment. He proposes the following:

1. **Reflect:** Make a list of what you are currently doing to manage the child's behavior. Are they working or not?
2. **Care:** Be personal and convey to the child that you are concerned about the misbehavior because you care.
3. **Focus:** Focus on the present behavior. Do not mention past behaviors. Ask "what," "how," and "who" questions. Limit the "why" questions.
4. **Value Judgement:** Do not preach, moralize or make value judgements about the child's behavior.
5. **Stop!:** When a problem occurs, teach the child to **STOP!** before the problem accelerates. Say "Please stop it, or Cool it".
6. **Question:** If step 4 does not work, say: "What are you doing? and "Is what you are doing helping you? If the child says nothing, say, "This is what I see you doing...., and it is not helping you.

7. **Plan:** Repeat Step 5 briefly and when it does not work, tell the child very firmly, "We have to work this out. That is our only option." Make time to talk with the child about a brief and simple plan. The plan has to be a positive plan of action that can help the child work toward responsible behavior.

8. **Thinking Time:** If the child is extremely agitated and is not listening to you, Step 6 will be ineffective. Your next step is to provide a "cooling off" place.

9. **Support:** Provide emotional, cognitive and physical support in helping the child achieve the goal. However, do not assume the child's responsibilities.

10. **Professional Help:** If the behavior is extreme, persistent and lasts over an extended period of time, seek professional help from social workers, counselors, psychologists, or psychiatrists.

*** Stop, Think, Plan, and Check (Cognitive)**

Children can be taught to monitor their own behaviors by using kitchen timers, sand timers, clocks, and wrist counters. They can be taught to chart their own behaviors and to analyze their progress. The Stop, Think, Plan, and Check steps can be used to decelerate inappropriate behaviors. The following is an example of these Thinking Steps:

Stop! Stop what you're doing. Put your present behavior on hold. Take a deep breath, or engage in a relaxation exercise, sing a song, count to ten, and so on.

Think! Think of the consequences. Is what you are doing helping you? Brainstorm alternatives.

Plan! Choose an alternative or two and make a plan. Implement the plan.

Check! Did your plan work. If yes, pat yourself on the back. If not choose another plan.

Conclusion

Discipline should always be implemented with dignity. In addition to a physical condition, children who are chronically ill experience psychological stress which frequently results in noncompliant, anxious and aggressive behaviors. Caregivers are often frustrated when these children resist treatment or appear uninterested in their care. They often question which discipline approach will gain compliance. The literature on behavior management provides numerous strategies based on various models of discipline. Knowledge of these models can enable caregivers to pick and select a strategy which best accommodates the situation and the maturity level of their patient. An effective behavior management plan should start with a least restrictive model of treatment. The manager can start with strategies from the Humanistic, Psychodynamic, or Ecological models and adapt more

restrictive measures from the Behavioral, Cognitive or Psychoeducational models as needed.

Collaborating with parents, and other service providers can result in greater understanding of the child's needs and solutions to problems. Positive communication and friendly interactions are critical to effective parent-professional partnerships and more importantly to the patient's welfare.

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